

Irish Haemophilia Society



Annual Report 2012

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A Message from the Chairperson

Each year the Society works very hard to maintain, develop and adapt all activities to suit the changing needs of the haemophilia community. 2012 was a year, that despite the continuing economic uncertainty, saw the Society deliver all of its scheduled activities with the continued professionalism that our members have become accustomed to. It was also a year that saw the introduction of the first phase of the Parents Empowering Parents (PEP) programme; a programme designed to provide parents with additional tools to successfully parent children with a bleeding disorder.

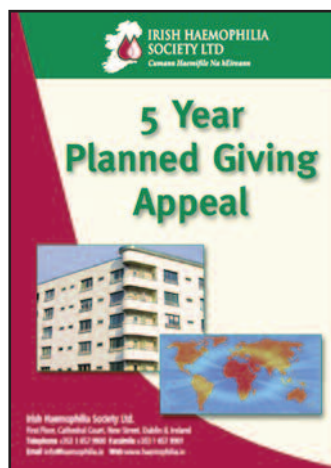


Traci Marshall Dowling,
Chairperson



Top: Michael Lynch, just one of the 11 men who took part in the IHS Movember Campaign 2012.

Bottom: The IHS Planned Giving Campaign is ongoing.



Fundraising

2012 was a really good year for fundraising and we want to say a big thank you to all those who worked hard to raise money for the Society. Members raised money from numerous activities during the year including the Gibraltar Straits Swim, a Silent Auction, the Great Northern Run in Newcastle, the Mini Marathon, Strictly Come Dancing and Movember.

The Society also signed up to the mycharity.ie website during 2012, based on the request of members. It is a web-based service for charities and fundraisers. This makes it as easy, simple and as safe as possible for people to make a direct donation online to their chosen charity. The fundraiser can create a unique fundraising page. To create your page you simply go to www.mycharity.ie and click on "create a fundraising page", choose your event date and name, choose your charity and fill in some details about your fundraiser and how much money you would like to raise.



The IHS signed up to mycharity.ie which allows fundraisers to get online sponsorship.

Planned Giving

We have a total of 38 members signed up for the planned giving 5 year appeal. Although the Irish Haemophilia Society (IHS) continues to face an uncertain financial future our member numbers are increasing and we continue to improve and increase our programmes, conferences and publications. 75% of the total amount raised will go towards the cost of apartment and the remaining 25% towards our twinning programme. Whilst the IHS has worked hard to expand and diversify our funding base to include additional corporate and fundraising income, we hope that the members of the Society continue to play an active role in the organisation's future by considering donating to the Society for a five year time period on a planned basis.

Hyde Square

The Society purchased a facility consisting of two properties, a two bedroom apartment and a separate one bedroom apartment. The apartments are located in Hyde Square, 200 metres from St. James's Hospital and less than a 5 minute walk from the National Centre for Hereditary Coagulation Disorders. This is beneficial for members travelling from outside of Dublin who have an early appointment or are attending appointments on consecutive days. The apartments are available to persons with haemophilia or related bleeding disorders during treatment or review. They are also available to immediate family members when a person with haemophilia or related bleeding disorder is an In-Patient in St. James's Hospital or in Our Lady's Children's Hospital, Crumlin. A nominal fee of €10.00 per booking per night will be levied to offset the cost of cleaning and routine maintenance. To book accommodation, please contact Anne Duffy, Debbie Greene or any staff member.

Educational Grants

Educational grants were introduced during the 1980's with two categories that people can apply for.

The 1st category, the Maureen & Jack Downey Educational Grant, is for people with haemophilia or related bleeding disorders and there are three grants of €4,000, €2,000 (Father Paddy McGrath Educational Grant) and €1,500 available. In order to qualify for the Maureen & Jack Downey Educational Grant applicants must be:

- o A person with haemophilia or related bleeding disorder.
- o Accepted on a post second level educational course.
- o Registered at the National Centre for Hereditary Coagulation Disorders at St. James's Hospital in Dublin.

The 2nd category is the Margaret King Educational Grant and is for immediate family members of people with haemophilia or related bleeding disorders and there are three grants of €2,000, €1,000 and €500 available. In order to qualify for the Margaret King Educational Grant applicants:

- o Must be an immediate family member of a person with haemophilia or related bleeding disorder.
- o Must be accepted on a post second level educational course.
- o Related person must be registered at the National Centre for Hereditary Coagulation Disorders at St. James's Hospital in Dublin.

What is the Application Process?

Applicants can apply each year and can also be repeat applicants. You can apply online or by post from 1st June 2013 and the closing date is Friday 13th September 2013. Applicants that are awarded a grant are notified by the end of October by letter.

What are the Application Assessment Criteria?

All applications are assessed on the following:

- o Quality of application.
- o Information given.
- o Financial need.
- o Applicants involvement (*or family involvement*) in the Irish Haemophilia Society.
- o How many in the family are going to college.
- o If applicant is applying for the first time.

Who Assesses The Application?

A sub group of three people from the executive board assesses all applications. The sub group cannot have a family member applying for any of the grants. The group bring recommendations back to the full board for agreement. The assessment is a transparent process with a scoring system in place, with all score sheets kept on file. All applications are treated in the strictest confidence and the process is reviewed each year.

WFH Congress

The World Federation of Hemophilia (WFH) Congress was held in Paris from the 8th to the 12th July 2012 with a record number of delegates, 5,400, attending from all corners of the world including 19 staff, board and members of the Irish Haemophilia Society. All those representing the Society participated in or attended talks in numerous areas. The IHS posters and publications were very popular with overseas delegates and some of our publications are being translated into other languages. The quality, professionalism and contribution of the IHS contingent was very evident during Congress week.



Some of the IHS Staff with WFH President Alain Weill from France.

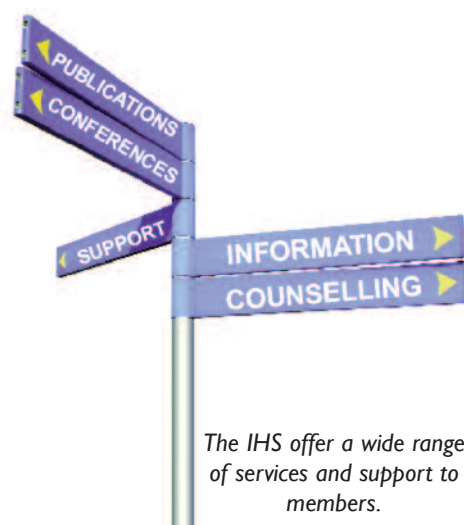
The sessions covered the following areas and topics: Global National Member Organisation (NMO) Training, Debates, Inhibitors, HCV / HIV setbacks and advancements, New approaches to the management of Hepatitis C, Sexual health, Preparing future generations, Ethics, Women with bleeding disorders, Adherence, WFH General Assembly, Gene therapy, Personalised prophylaxis, Ageing and Economics.

When I attended the WFH Congress in 2008 I was struck by the stark contrast between the developed and developing worlds, and came home a little overwhelmed by the challenges and tasks that faced both the haemophilia community and the medical teams treating them. Thankfully this time around I'm happy to report that I was heartened to see the real difference that time can make and it was great to see the huge strides made by countries that I once thought had very poor outlooks. I know I'm in danger of sounding very cheesy, but by communities working together on both a national and international level it really is possible to bridge the gap!

Services to Members

Often people need support dealing with diagnosis, especially when there is no known family history. Other times, previous negative experience has, understandably, skewed people's views and opinions about haemophilia so additional support may be needed. In addition to this and, thankfully, more positively we are now moving into a new era of haemophilia treatment and care with new outlooks and opportunities being a real possibility for our members. We strive therefore to be as flexible and adaptable as possible to the changing needs of the Society and we currently offer the following support and services to people with bleeding disorders and their families:

- o Counselling
- o Dealing with diagnosis
- o Bleed recognition
- o Educational programmes
- o Information programmes
- o Regional / outreach visits



Conference attendance

We are now seeing an increase in the number of members booking in for our conferences. With clinical trials, longer acting products and new hepatitis C treatments rapidly moving from discussion to reality, our conferences provide an opportunity to get the most up to date information from the experts and allow members to discuss any challenges or opportunities that arise from these new developments. It is great to see that our numbers are increasing and that the Society continues to maintain its strength and vibrancy.

I.H.S. Board

The board continue to represent all areas of the membership, and continue to be very committed, with excellent attendance at monthly meetings. 2012 was a year that two members stepped down from the board, but fortunately we also gained three new members. Michael Davenport decided it was time to hang up his boots and take to the wonderful world of travel and Brian Byrne also decided to step down this year. On behalf of the board I would like to thank Brian and Michael for all their contributions and hard work over the years. John Stack and Sarah Gilgunn were welcome new additions to the board and Michael Butler was a welcome return. I would like to thank all the board for their continued hard work and dedication throughout 2012.

I.H.S. Staff

Finally I would like to finish up with a big thank you to Brian, Debbie, Anne, Nina, Declan, Nuala and Fiona. Their continued energy, dedication, professionalism and commitment throughout 2012 ensured we got the best support and services that the Society had to offer.

Traci Marshall Dowling
Chairperson

Honorary Secretary's Report

At the 23rd Annual General Meeting of the Irish Haemophilia Society, (IHS) which was held in the Lyrath Estate Hotel in Kilkenny on Saturday the 3rd March, 2012 the incoming Governing Body of the Society were elected as follows:-



Traci Marshall Dowling,
Chairperson



Brian O'Riordan,
Vice-Chairperson



Gerard O'Reilly,
Treasurer



Mary Hanney,
Secretary

At the first executive meeting following the AGM on 16th April, 2012, the following Officers were elected:-

Chairperson
Traci Marshall Dowling

Vice-Chairperson
Brian O'Riordan

Honorary Secretary
Mary Hanney

Honorary Treasurer
Gerard O'Reilly



Brian Byrne



Eoin Moriarty



John Stack

In the period since the last AGM, thirteen executive board meetings were held, which included two conference calls.

MEETINGS ORGANISED BY THE SOCIETY

IN MARCH, 2012

The 23rd Annual General Meeting and Conference of the Irish Haemophilia Society took place over the weekend of the 2nd to the 4th of March in the Lyrath Estate Hotel in Kilkenny.

The weekend was a great success with attendance up by 26% from 2011. There was an excellent programme over the weekend which included lectures on 'Orthopaedic Surgery', 'Clinical Trials', 'Haemophilia in our Twin Country of Vietnam', an 'Open Forum discussion with the Comprehensive Centres' and a session on the 'Future of the Irish Health Service'.

The children's groups had a great time doing lots of activities which included swimming, playing games, some education and a treasure hunt. The Youth Group also had a great time doing team building activities and swimming.

The Gala Dinner was very enjoyable after which a special presentation was made to Brian O'Mahony for his 'Extraordinary service to Irish people with haemophilia for over 30 years' which will now continue as the 'Brian O'Mahony Award for Outstanding Contribution to the Haemophilia Community in Ireland', in recognition of other exceptional people connected to the Irish Haemophilia Society.



Traci Marshall Dowling, Chairperson, presenting IHS CEO, Brian O'Mahony with the Brian O'Mahony Award for 30 years of extraordinary service to haemophilia.

IN APRIL, 2012

The Society organised regional and home visits during April to different locations. The I.H.S. are aware that not everyone can attend events, so these visits are a very important way of keeping in touch with members who may need information or just a friendly chat.

IN MAY, 2012

The Parent's Conference was held in the Sheraton Hotel in Athlone from May 11th to 13th. This was a very enjoyable weekend with very good talks on 'Trials for a longer lasting factor', 'Bullying' and a talk by Dr. Mai on 'People living with haemophilia in Vietnam'. The 'Mother's workshop' was also very well received with plenty of discussion. There was very positive feedback after this weekend which was great to hear.



Dr. Mai & Ms. Hanh from the Vietnamese Society for Congenital Bleeding Disorders spoke to the adults and children at the Parents Conference.

A HIV/Hepatitis C conference took place over the weekend of May 25th to 27th in the Hotel Kilkenny. Along with staff and speakers from St. James's Hospital 18 members (including some spouses) attended the conference. The programme was packed with excellent talks including 'Updates on treatments', the 'Practical management of treatments', workshops on 'Personal perspectives on treatment' and 'The psychological management of going on treatment'. There was also an excellent informative session on the HAA Card and the support this offers. This was the second such weekend for this group of members and it will be repeated again in May 2013.

IN JUNE, 2012

The ladies were out again strutting their stuff on Leeson Street taking part in the Women's Mini Marathon on the 4th of June. There was a great turnout and everyone had a great day. The money raised was most welcome by the Society, who would like to thank everyone who took part and raised funds.

IN SEPTEMBER, 2012

On the 8th and 9th of September a conference was held in the Clarion Hotel Liffey Valley in Dublin for young men with haemophilia aged between 18 and 35 years of age. The first conference in 2011 was very successful and as a result a second conference was held. There were talks on 'Fitness', 'Health', 'Sport', 'Relationship Issues' and 'What benefits are available and how to access information' provided by the Citizen's Information. There was also an 'Open Forum' where the main topic discussed was travelling abroad and the importance of travel insurance. This weekend was a great success again.



The lovely ladies of the IHS were out in force again for the 2012 Women's Mini Marathon.

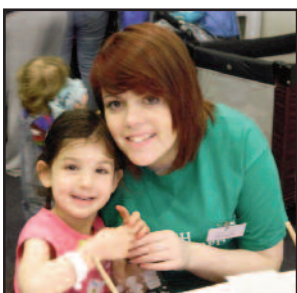
IN OCTOBER, 2012

The Member's Conference took place from the 12th to the 14th of October in the Heritage Hotel, Portlaoise and everyone attending seemed to greatly enjoy the weekend. The topics covered at this conference were 'Getting the most out of your haemophilia treatment' and 'Haemophilia – The impact on the family'. These were very open discussions with everyone sharing their different experiences. There was also a very good debate on 'Who knows better the doctor or the patient?' which was enjoyed by everyone. The Children's Groups had lots of activities to keep them entertained and the Youth Group went to at the Lilliput Adventure Centre for the weekend.

IN NOVEMBER, 2012

A Memorial Service was held in the office of the Society on the 4th of November in memory of our members who have passed away, but who are by no means forgotten. They were remembered for the light and joy that they brought to the lives of their loved ones.

Two PEP Conferences were held in the City North Hotel, Co. Dublin from the 16th to the 18th of November and from the 23rd to the 25th November. This programme which is called 'Parents Empowering Parents' (PEP) was described as fantastic. This was about parents sharing their experiences, advice and what worked for their families. It was about parents who share the same worries and problems in their lives supporting and encouraging each other. These two weekends were very successful.



Some of the 32 IHS volunteers who helped out during 2012.

The organising of these conferences would not be possible without the valued assistance of all our volunteers, which now stands at forty five. Their help and support are really appreciated and the Society wishes to thank them all.

CONFERENCES AND OTHER EVENTS

During the course of the year the Society was represented at a number of other events as follows:

The World Federation of Hemophilia Congress (WFH) was held in Paris from the 8th to the 12th July, 2012. The Society was represented by the staff, some of the board and also some members.

The Annual European Haemophilia Consortium (EHC) conference took place in Prague on October 26th to the 28th. Three board members Traci Marshall Dowling, John Stack and Gerard O'Reilly attended along with Brian O'Mahony and Declan Noone.

WEBSITE

The Society's website is updated regularly with all the latest information including events and what is happening in the Society.



The IHS library is filling up fast. In 2012 the IHS produced 14 publications, all of which can be downloaded from the IHS website.

PUBLICATIONS

The Society had a busy year with its publications issuing:

- | | |
|--|------------------------------|
| o Planned Giving leaflet | o Spring Magazine |
| o Annual Report | o Haemophilia Heroes |
| o Hepatitis C Supplement "Positive News" | o Sibling Superstars |
| o Summer Magazine | o Mild Haemophilia |
| o Portacaths booklet | o Autumn Magazine |
| o Winter Magazine | o WFH Congress Supplement |
| o Wallet sized contact cards; OLCHC | o 8 Posters for WFH Congress |

All publications, including those already issued, can be downloaded from our website or can be obtained in hardcopy from the office.

GRANTS & SCHOLARSHIPS

Our grants & scholarships programme is proving very successful and a total of €17,750 was paid out in 2012.

Right: Lorraine O'Connor receiving the Margaret King Educational Scholarship from IHS Chairperson, Traci Marshall Dowling.



Far Right: Patrick Browne receiving the Maureen and Jack Downey Educational Grant from IHS Treasurer Gerard O'Reilly.



I.H.S. STAFF

The Irish Haemophilia Society staff have done a fantastic job this year keeping the show on the road with their professionalism and hard work and they are very much appreciated.

The Current Society Staff are:



Brian O'Mahony,
CEO



Debbie Greene,
Administrator



Anne Duffy,
Counsellor



Nina Storey,
Administrative
Assistant



Declan Noone,
Administrative
Assistant



Nuala McAuley,
Administrative
Assistant



Fiona Brennan,
Administrative
Assistant

SOCIETY REPRESENTATION

The Society is represented on a number of external committees as follows:

National Haemophilia Council – Brian O'Mahony & Debbie Greene

Haemophilia Product Selection and Monitoring Advisory Board – Brian O'Mahony & Declan Noone

Haemophilia HIV Trust – Brian O'Mahony & Nina Storey

Disability Federation of Ireland – Debbie Greene

World Federation of Haemophilia – Brian O'Mahony, Anne Duffy & Declan Noone

European Haemophilia Consortium – Brian O'Mahony

Consultative Council on Hepatitis C – Anne Duffy

The board would like to express its thanks to the staff, for their continuing commitment and for representing the best interests of the Society.

We also wish to acknowledge with gratitude all donations received during the year and the efforts of our fundraisers. We understand that fundraising is very difficult in today's climate, but all efforts are greatly appreciated and hopefully things will improve as we look forward positively to the rest of 2013.

Mary Hanney
Honorary Secretary

www.haemophilia.ie



Back to the Future

In October 2012 a familiar face returned to the IHS, when Michael Butler rejoined the board after a three year break. Michael has two sons with haemophilia and has been involved with the Society for over 20 years. With a background in disabilities and service management, Michael is guaranteed to help steer the IHS to a promising future.

Welcome Back Michael!



IHS International

The IHS work with other National Member Organisations (NMOs) to ensure that optimum support is delivered to members. In 2012 the IHS welcomed delegates from the Haemophilia Foundation of New Zealand. During the visit, workshops took place on Outreach, Publications and Events.

New Kids on the Block

Following a review of the programmes for children and young adults, a need was recognised for a fourth children's group and the Cubs Club was born.

With four children's groups, the IHS can deliver education and information in an age appropriate way.



ID Please

The IHS, together with NCHCD launched the Severe Bleeding Disorder Alert Card in March 2012. The Alert Card will help to improve haemophilia care in Ireland and is a prime example of the ongoing advocacy work the IHS does.



New to the Society in 2012

At the AGM in March, John Stack, father of three, including two boys with haemophilia, was elected to the board of the IHS. An engineer and a strength & conditioning specialist, John has an interest in promoting safe exercise tips to members, and has already talked on the subject at HIS IHS 2012.

John didn't hold the "newbie" title on the board for long as in April 2012, IHS member and volunteer Sarah Gilgunn was co-opted onto the board. Sarah has volunteered with the Society for two years and received the Margaret King Educational Grant in 2011. Sarah is currently doing a PhD and is very interested in gene therapy and genetics.



Home Away From Home

The IHS is dedicated to providing the best services and support to its members. In 2012 a need for accommodation in Dublin was recognised and in June 2012 the IHS purchased two apartments in Hyde Square, situated just five minutes from St. James's Hospital. The two bedroom and studio apartments are available for members of the IHS who require accommodation when attending clinics or appointments in NCHCD or OLCHC.



Perfect Match

The Irish Haemophilia Society and the Vietnamese Society for Congenital Bleeding Disorders were awarded Twin of the Year for 2012 by the World Federation of Haemophilia.

The award comes in the third year of the Twinning Partnership between the two organisations, which will run until 2014.



The In Crowd

Work on the new In-Patient Unit in St. James's Hospital began in the Summer of 2012. The unit, which is due to open in April 2013, will have six beds specifically for patients with haemophilia and related bleeding disorders.

The Irish Haemophilia Society have been involved in the development of the unit contributing on areas such as layout and patient needs.

The unit marks a new chapter in haemophilia care in Ireland.



Ten out of Ten

For the second time, the IHS took part in the Better Together Video Campaign.

This year the IHS video focused on the Twinning Partnership between the IHS and the Vietnamese Society for Congenital Bleeding Disorders and finished in the top 10 of over 100 entries. A huge thank you to everyone who supported the IHS in the campaign.



The Year in Review from our CEO



Brian O'Mahony
Chief Executive

The year 2012 was again busy and productive for the Society. Our conference attendance and the number and diversity of our publications reached record levels. Our advocacy work on the availability of the new generation of hepatitis C treatment bore fruit after intensive work, and new and exciting opportunities were opened up to members during the year when the first participants enrolled in clinical trials for longer acting factor concentrates. Discussions were also held on the prospect of participation in clinical trials for gene therapy in factor IX deficiency. Our strategic plan for 2011 to 2014 is well on schedule. The plan contains a total number of strategies of 150 and to date 110 (73%) of these strategies have been completed, are ongoing or are annual activities.

CONFERENCES

AGM and Annual Conference

Registrations for the the AGM and Annual Conference in 2012 were 240 comprising of 175 adults and 65 children or teenagers. This attendance was a very significant increase of 26% from the 2011 attendance of 186. This increase in registration is a positive and an ongoing indication of a high level of member involvement in and engagement with the organisation. Among the topics focused on were mild haemophilia, von Willebrands disease, new factor treatments, clinical trials and inhibitors. At each Society residential conference or event, specific programmes are organised for adults, teenagers and children, and a crèche and young children's programme is also organised. In 2012, we saw an increased attendance at our two major weekend residential conferences (AGM & Conference and Members' Conference). This was partly due to the year round impact of the parents conference. This conference introduces a number of new families to the organisation annually.

Many of these families subsequently attended the Members' Conference in October. In 2012, the attendance at the Members' Conference was 197 people comprising of 123 adults, and 74 children or teenagers. This constituted an 8% increase over the 2011 attendance. The members see this as a less formal conference with more proactive participation by members. The lectures and sessions are more focused on sharing of personal experiences and empowerment by example. In 2012, the focus of the conference was getting the most from your treatment, a debate among two members on the relative roles of doctors and patients and a family experience workshop designed to identify the differing perspectives of people with bleeding disorders, siblings, partners, carriers, parents and relatives.

Parents Conference and Parents Empowering Parents (PEP) programme

The parents of children and teenagers with haemophilia face many challenges. These include having to learn to recognise the early symptoms of joint or muscle bleeds, learning to infuse the child at home including techniques for intravenous infusion and proper use and maintenance of indwelling venous access devices. They have to encourage the older child to learn self treatment, deal with the transition from paediatric to adult services and compliance with treatment by children and teenagers. The Parents Conference, organised for the fourth time in 2012, was again a resounding success. The total attendance was 128, including 82 adults and 46 children.

The evaluations were uniformly positive. The conference gave parents an opportunity to be educated about some of these vital issues, to learn from the healthcare workers in attendance and to learn



Top: One of the highlights at the Parents Conference was the Self Infusion Workshop.

Bottom: Attendances at IHS Events increased in 2012.



from the life experiences of each other. The programme in 2012 included a self infusion workshop, symposia on clinical trials and the economy, and a workshop on bullying and disclosure. This co-operation with the key paediatric centre staff is a key element in the success of the conference. All of the sessions lead to vigorous discussion and it is always particularly pleasing to see parents clearly learning from each other and reflecting and learning from the past experiences of other parents. We were very pleased to once again welcome 2 families from Northern Ireland.

In 2012, we also organised two Parents Empowering Parents (PEP) conference's. This new departure is a recognition that there are an increasing number of children being born with severe haemophilia due to new mutations in families with no family history of haemophilia and therefore no inbuilt coping skills. In the past, up to 30% of newly diagnosed children with haemophilia had no family history. This is now closer to 50%, so there is an ever increasing need for education to increase the parents understanding of their child's bleeding disorder. The rationale for the PEP approach is that we train nurses, social workers and parents in the first instance to provide the training and they then become the facilitators. This was the case in 2012. The objectives of PEP are:



Fourteen parents took part in the PEP Training. Four parents then went on to become PEP Trainers.

- * To provide the parent with the skills necessary to effectively parent the child at the earliest age possible.
- * To heighten the parents ability to respond objectively and consistently to bleeding objectives and behavioural issues.
- * To enhance the therapeutic relationship between parent, child and treatment centre staff.

In 2012, a specific conference was organised for men with haemophilia in the 18 to 35 age group which included symposia on fitness, benefits and relationships. This conference for young men with haemophilia was again a success. A total of fourteen young men attended and fully engaged with the programme. Many of these young men are now starting to attend our other conferences and events.



HIS IHS took place for the second year in a row. Fourteen men with bleeding disorders aged between 18 to 35 attended the meeting.

We also organised a special conference for members with HIV and / or hepatitis C which included lectures and workshops focused on the new generation of hepatitis C treatments.

Our conferences could not run successfully without the commitment and hard work of our staff and our 45 active, trained and committed volunteers who work hard at the conferences with the teenagers and children.

AVAILABILITY OF TREATMENT

Our work on the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) continued and the new contract for the supply of recombinant FVIII came into effect in 2012. It is worth noting that our work on the HPSMAB has contributed significantly to saving the country many millions of euro's over the past ten years due to our advocacy for and implementation of a more competitive and cost effective National Procurement Process. It is particularly worth noting that our work on the design of the scoring system and our information on comparative prices globally led to a very cost effective national procurement for Recombinant Factor VIII and very significant savings. Further savings were made in 2012 when, at the behest of the IHS, the contract holder for the purchase of factor concentrates was changed from the Irish Blood Transfusion Service Board to St. James's Hospital, thus eliminating handling fees.

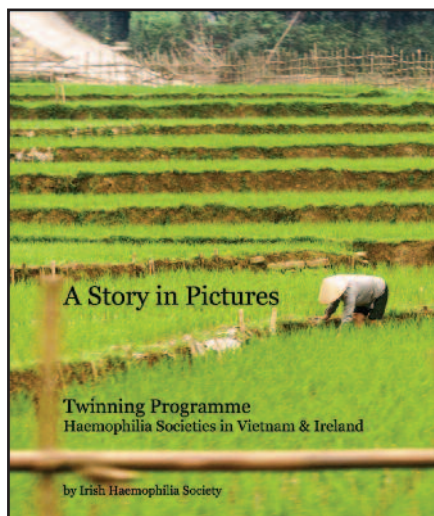
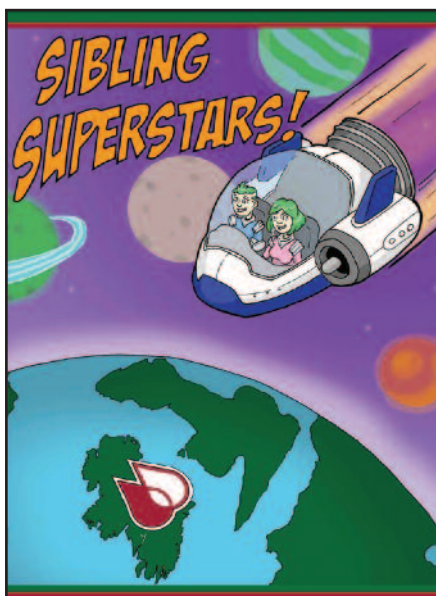


IHS CEO Brian O'Mahony and Minister for Health James Reilly on World Haemophilia Day.

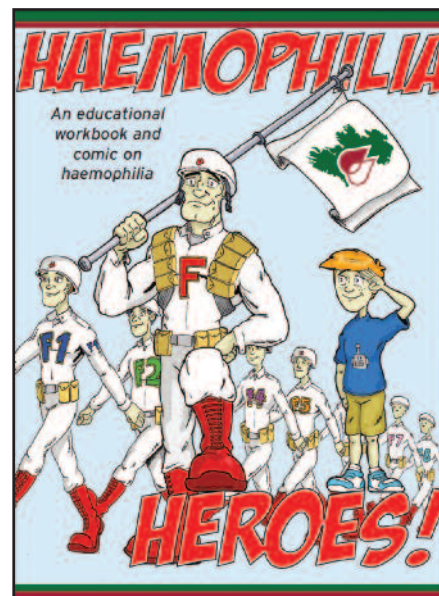
The availability of the new generation of hepatitis C treatments was a priority for the Society in 2012 and on World Haemophilia Day on April 17th, we met with Minister James Reilly who approved the availability of the treatments at that meeting. Following the decision, we worked on many levels with the Department of Health (DOH), with the clinicians and with the Health Service Executive (HSE), to try to minimise the delays between the decision and the actual availability of therapy. This was a long and frustrating process where unexpected delays constantly occurred, but eventually members started getting access to treatment. It is an indication of the changed healthcare landscape that we had to exert so much time and energy into ensuring the implementation of a decision already made by the Minister. Following the availability of therapy, we provided optimum support on an individual and collective basis to all our members on treatment. I also represent the society on the Irish Hepatitis C Outcomes Research Network (ICORN) who will oversee the clinical results of the treatment programme.

PUBLICATIONS AND WEBSITE

Specific publications are produced based on our knowledge of the current requirements, following discussions with the Comprehensive Care Centres where clinical input is required and in line with our Strategic Plan. In 2012, we produced 14 specific publications.



The IHS produced 14 publications in 2012, all of which can be downloaded from the IHS website.



The range and diversity of our publications continues to increase with the objective of providing up to date and useful information to all demographic groups within our diverse membership. In addition, the Society were responsible for 6 scientific peer reviewed papers which were published (or were accepted for publication by the end of the year) in scientific journals including the journal *Haemophilia*.

The I.H.S website, www.haemophilia.ie, is updated regularly with information on haemophilia and related bleeding disorders, including relevant media articles which are updated on a daily basis and articles which appear in the newsletter are often published on the website in a more detailed format for members who have a specific interest in these areas.

COLLABORATION ON NATIONAL CARE

The Society continue to work closely and collaboratively with the centres, the National Haemophilia Council and the HSE and the Department of Health on the development of treatment and care on a national basis. We liaise regularly with National Director Dr. Barry White and the directors and staff at the comprehensive care centres. Team meetings with the centres and meetings with the Chief Executives of the hospitals which host comprehensive centres were again held in 2012. We are delighted with the progress made in the building of the new national In-Patient unit for haemophilia and hepatology which proceeded on schedule in 2012 for a planned opening in the first half of 2013. The Society have been fully involved and engaged in discussions and design of the new facility which will make a major difference to the in patient experience.



The IHS apartment is available to all members of the IHS and is located 5 minutes from St. James's Hospital.



The Twinning Partnership between the IHS and the Vietnamese Society for Congenital Bleeding Disorders is now in its 3rd year. In 2012 the IHS and the Vietnamese Society for Congenital Bleeding Disorders were awarded Twin of the Year by the WFH.

Other notable developments during the year included the opening of the Society apartment adjacent to the National Centre in St. James's hospital as a much needed facility for members. This has allowed and will allow members who require accommodation close to St. James's for treatment purposes or family members visiting those in hospital in St. James's Hospital or Our Ladys Childrens Hospital, Crumlin to stay in a convenient facility.

Our twinning programme with the Vietnamese Society for Congenital bleeding disorders was very active. Achievements included the provision of training workshops in Vietnam for chapter leaders and key volunteers and an agreed new governance structure for the organisation in Vietnam. Our twinning programme in 2012 was selected as the Twin of the Year by the World Federation of Hemophilia (WFH) from among the 16 active twinning programmes.

Future developments in replacement therapy came closer to reality in 2012 as several Irish children with severe haemophilia began participation on final phase clinical trials for longer acting factor concentrates and the Society, together with Dr. White, organised specific meetings for people with haemophilia B to discuss their possible participation in a clinical trial for factor IX gene therapy.

Financially, we had a challenging but solid year of achievement where a slight decrease in funding from the Health Service Executive was balanced by greater corporate sponsorship and a successful beginning to our planned giving programme from our members and supporters.

Overall, 2012 was a year of solid achievement against a difficult economic backdrop both nationally and internationally.

Brian O'Mahony
Chief Executive

Independent auditor's report to the members' of The Irish Haemophilia Society

We have audited the financial statements of The Irish Haemophilia Society for the year ended 31st December 2012 which comprise of an income and expenditure account, balance sheet, cash flow statement and related notes. These financial statements have been prepared under the accounting policies set out therein. This report is made solely to the company's members, as a body, in accordance with the requirements of the Companies Acts 1963 to 2012. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the company and the company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of directors and auditors

As described in the statement of directors' responsibilities the company's directors are responsible for the preparation of the financial statements in accordance with applicable law and Accounting Standards issued by the Accounting Standards Board. Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and International Standards on Auditing (United Kingdom and Ireland). We report to you our opinion as to whether the financial statements give a true and fair view in accordance with Generally Accepted Accounting Practices in Ireland and are properly prepared in accordance with the Companies Acts 1963 to 2012. We also report to you whether in our opinion: proper books of account have been kept by the company; whether, at the balance sheet date, there exists a financial situation requiring the convening of an Extraordinary General Meeting of the company; and whether the information given in the Directors' Report is consistent with the financial statements. In addition, we state whether we have obtained all the information and explanations necessary for the purposes of our audit and whether the company's balance sheet and its income and expenditure account are in agreement with the books of account. We report to the members' if, in our opinion, any information specified by law regarding directors' remuneration and directors' transactions is not given and, where practicable, include such information in our report. We read the directors' report and consider the implications for our report if we become aware of any apparent misstatements within it.

Basis of audit opinion

We conducted our audit in accordance with International Standards on Auditing (UK and Ireland) issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made by the directors in the preparation of the financial statements, and of whether the accounting policies are appropriate to the company's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements. We have undertaken the audit in accordance with the requirements of APB Ethical Standards - Provisions Available for Small Entities, in the circumstances set out in note 11 to the financial statements.

**Copies of the full audited accounts for
2012 are available on request.**

Registered Office

Irish Haemophilia Society Ltd., First Floor,
Cathedral Court, New Street, Dublin 8.
Company Number: 142834
Registered Charity Number: CHY9214

Auditors

Howlin, O'Rourke & Co
Certified Public Accountants &
Registered Auditors,
4 The Seapoint Building, Clontarf, Dublin 3.

How we used the money

AGM & Meetings	20%	
Members Conferences & Meetings	16%	
Publications & Website (Includes database, research & data collection)	16%	
Counselling & Support	13%	
Financial Support to Members	9%	
Representation on Statutory & External Bodies	8%	
International Development Assistance	7%	
Establishment / Headquarters	6%	
Administration & Finance (Includes Fundraising)	5%	



Income & Expenditure Account For The Year Ended 31st December 2012

	2012 €	2011 €
Income		
Health Service Executive	549,448	577,396
NCHCD Educational Fund	-----	24,000
Memberships	3,980	3,710
Donations - Members	75,282	23,820
Donations - Corporate	69,279	47,410
Twinning	6,015	10,760
Fundraising	19,792	8,729
H.H.T.Trust	-----	12,750
Investment Income	13,236	35,644
Sundry Income	1,000	-----
	<u>738,032</u>	<u>744,219</u>
 Expenditure as per schedule	 <u>(732,836)</u>	 <u>(659,438)</u>
 Surplus for the year	 <u>5,196</u>	 <u>84,781</u>





	2012		2011	
	€	€	€	€
Administration Expenses:				
Wages, State Insurance and Pension Costs	225,986		225,076	
Employer's PRSI Contribution	23,672		21,604	
Office Expenses & Stationery	9,933		16,618	
Telephone & Fax	9,510		9,280	
Travelling Expenses	5,643		5,019	
Overseas Travel Expenses	6,654		11,575	
I.H.S. Members' Facility	2,234		-----	
Sundry Expenses	7,137		5,211	
		290,769		294,383
Financial Expenses:				
Bank Charges & Loan Interest	2,332		4,586	
Professional Fees	83,913		86,649	
Audit & Accountancy Fees	5,535		5,535	
		91,780		96,770
Activities:				
Help to Members	22,569		25,470	
H.H.T. Trust	9,500		6,750	
Subscriptions	1,777		1,495	
Fundraising Expenses	1,285		1,365	
A.G.M. & Meeting Expenses	37,298		35,330	
Postage, Publications & Photocopying	41,681		23,694	
Educational Grants	17,750		16,000	
Safety/Supply Activities	1,669		8,988	
Counselling & Support Meetings	4,455		14,304	
Twinning	13,440		6,283	
Website	2,799		4,509	
WFH GAP Program/Development Grants	17,804		7,264	
Sponsorship/Training	5,060		1,515	
Parent's Conference	17,075		17,338	
Members' Conference	24,775		21,496	
HIV/HCV Conference	4,699		-----	
PEP Conferences	6,531		-----	
HIS Conference	2,350		-----	
		232,517		191,801
Establishment Expenses:				
Service Charge & Insurance	15,534		16,056	
HQ Costs	489		2,200	
Computer Services	12,858		9,510	
Light, Heat & Services	11,367		13,700	
		40,248		41,466
Other Costs:				
Depreciation - Fixtures, Fittings & Equipment	3,068		8,736	
Depreciation - Land & Buildings	74,454		26,282	
		77,522		35,018
Total Expenditure		732,836		659,438

	2012 €	2011 €
ESB Mortgage Account:		
Opening Balance 01.01.12	74,179	171,142
Interest Charges	557	2,824
Monthly Repayments (Capital & Interest)	<u>(74,736)</u>	<u>(99,787)</u>
Closing Balance 31.12.12	Nil	74,179

Balance Sheet As At 31st December 2012

		2012 €	2011 €
Fixed Assets:			
Buildings	Note 5	1,242,933	1,142,387
Office Equipment & Fittings	Note 5	<u>12,271</u>	<u>-----</u>
		1,255,204	1,142,387
Current Assets:			
Davy Investment Portfolio		170,000	170,000
Allied Irish Bank-Current Account		82,706	296,215
Allied Irish Bank-Planned Giving Current Account		32,083	16,771
Allied Irish Bank-Deposit Accounts		194,200	186,476
Permanent TSB-Deposit Account		187,560	187,560
Cash on Hand		263	95
Sundry Debtors & Prepayments	Note 6	<u>8,772</u>	<u>5,275</u>
		675,584	862,392
Current Liabilities:			
Sundry Creditors & Accruals	Note 7	<u>(106,698)</u>	<u>(111,706)</u>
		<u>(106,698)</u>	<u>(111,706)</u>
Net Current Liabilities		568,886	750,686
Long Term Liabilities			
Long Term Property Loan	Note 8	<u>-----</u>	<u>(74,179)</u>
Net Assets / (Liabilities)		<u>1,824,090</u>	<u>1,818,894</u>
Represented By:			
Accumulated Funds			
Balance 1st January 2012		1,818,894	1,734,113
Surplus for the year		<u>5,196</u>	<u>84,781</u>
Balance 31st December 2012	Note 9	<u>1,824,090</u>	<u>1,818,894</u>



CORPORATE SPONSORS

The Irish Haemophilia Society would like to acknowledge the unrestricted financial contributions made in 2012 by the following companies under our Corporate Giving programme.

Platinum Sponsors

Baxter, Pfizer

Gold Sponsors

Bayer, CSL Behring, Novo Nordisk

Silver Sponsors

Inspiration (ISPEN), Merck, Swedish Orphan Biovitrum

FUNDRAISERS

The Irish Haemophilia Society would like to acknowledge and thank with gratitude everyone who fundraised for the Society during 2012, as follows:

Amy Dunne, Amy Phipps, Angela Keane, Audrey Bridgeman, Barbara Wynne, Carly Wright, Connall McGleenan, Debbie Nesbitt, Deirde Phipps, Jackie Wright, Jacqueline Reid, Jason Murphy, Jonathan Touhey, Karla Cox, Katie Mooney, Kieran McHugh, Leighton Ryan, Lisa May, Mary Hanney, Michael Burke, Michael Carty, Michael Lynch, Nina Storey, Pallavi Phoenix, Paul Griffiths, Paula Smith, Rose Boyle, Sandra Phipps, Sara Andrews, Sarah Clohessy, Sarah Griffin, Seamus Collins, Sharon Farrelly, Tom Sheerin, Trish Cox, Veronica Dunne.

VOLUNTEERS

The Irish Haemophilia Society would like to acknowledge and thank everyone who volunteered for the Society during 2012. Their help and support are very much appreciated.

EVENTS

Aisling Moriarty, Aislinn Farrelly, Amy Carroll, Andrew Manifold, Aoife Carey, Aoife Conway, Cathal Rochford, Catriona Moriarty, Ciaran Dowling, Claire Moriarty, Claire Neill, Daniel Carey, Deirdre Ryan, Denise Goslin, Denise Maher, Donal Glackin, Donal McCann, Eoin Moriarty, Erika Nasickyte, Lucia Prihodova, Niamh Mangan, Paul Dunne, Sam Morrissey, Sarah Charnock, Sarah Gilgunn, Seamus McDonald, Shannon Doyle, Shauna Keniry, Shawna Chapman, Stephen Boylan, Teresa Howes, Tricia Moran.

PUBLICATIONS

Anthony O'Connor, Mary Flanagan, Michael Davenport, Orlagh McGleenan, Sharon Farrelly, Shay Farrelly.

PLANNED GIVING 5 YEAR APPEAL

The Irish Haemophilia Society gratefully acknowledges and thanks the following people who donated to our 'Planned Giving 5 Year Appeal' during 2012.

Anne Brennan, The Campbell Family, In memory of Richard & Paul Costello, The Cox Family, The Crowe Family, Con Curtin, The Davenport Family, The Farrelly Family, The Fay Family, In memory of Andrew Finlay, Nodlaig Griffin, The Guilfoyle Family, Ann McCabe, Stephen, Daniel & Joyce McEvoy, Brendan McGuinness, Kieran McHugh, The Moloney Family, Patrick Murphy, Brian O'Mahony, In memory of Sheila O'Mahony, Gerard O'Reilly, Brian O'Riordan, In memory of Patrick Owens, The Sheerin Family, The Stack Family, Anthony Smullen, In memory of Donal Twomey, The Wynne Family.

Eighteen anonymous members also donated to our 'Planned Giving 5 Year Appeal' during 2012, for which we are very grateful.

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